Lessons From the Practice

The Importance of Hope

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hundred years ago, when I was a medical student on the general medicine wards, a 55-year-old woman was admitted to my service with a coin lesion in the right upper lobe of the lung. She was basically well and asymptomatic and spent the next week undergoing diagnostic studies—bronchoscopy and so forth. During that time, I got to know her and like her. She was a real dynamo, vigorous and friendly. She became the extra pair of hands on the ward, helping to pass the meal trays, running minor errands. We all came to love her. When the diagnostic tests came back nondiagnostic, the patient was transferred to the surgery service and underwent an open thoracotomy. At operation, she was found to have a squamous cell carcinoma that had already invaded the mediastinal nodes, such that the tumor was not resectable. A biopsy was taken, and the incision was closed.

I was dreading the next morning; I was afraid to see her because I didn't know what to say-what words to use. I chose to wait, and I went into her room for the first time with the resident and interns. The resident stood at the side of her bed—think of that for a moment—stood there, looking down at her—not looking at her—try that sometime. I will tell you that it feels bad to have someone standing over you as you are lying in bed or sitting in a chair, talking down to you. In any event, he stood there and said, "Well, it's cancer, and we couldn't really resect it, so we just opened and closed." She asked, "Opened and closed?" He said, "Yes, well, it couldn't be removed, so we just closed." She kept repeating the words to him, and he kept nodding his head and confirming what he had said. "You mean you left the cancer there?" "Yes." She closed her eyes, said that she was tired, and the team walked out of the room.

When I went back to see her, she gave me a little small talk, but basically, she was just not the same person, and I was too young and inexperienced to know what to do. When I came in the next morning, I learned that she had died during the night. She was taken to autopsy, but there was no actual specific cause of death—just the cancer, which most certainly had been there for many months.

I have never been able to get her words out of my mind, "You opened and closed? You mean you left the cancer there?" I don't really know why she died, but to be honest, I will always believe that she died because all hope had been taken away from her. And I also believe that the key in that case was that the resident had said to her that she had cancer and that there was nothing that could be done. He obviously had taken her through a major operative procedure, and she had the pain and the scar to prove it, but nothing had been done. Furthermore, the resident never mentioned to her or

suggested in any sense that there was any other treatment that could be used. His words took away her hope, and I honestly believe, as crazy as it may seem, that those words took away some of her potential lifetime.

Should he have lied to the patient? No, I don't think so, but I do think that we can be sensitive to the effect of our words, and that it might be acceptable to state the facts in such a way that we do not take away all possibility of hope. For example, why couldn't the resident have said that he removed some of the tumor but could not remove all of it, and, therefore, that further therapy would be required. That's all; that's not a lie. It states the facts as they occurred but still allows the patient some space in which to work, some possibility of life ahead.

Let me give one more example of this concept of hope, to illustrate that even if the patient does die, the time that he or she is given will be spent better if the patient has been allowed some hope, as opposed to spending the remaining lifetime in a state of perpetual fear that each day is supposed to be the last.

In 1982 a 30-year-old attorney was referred to me with a diagnosis of T-cell immunoblastic sarcoma. He had seen several physicians who had basically said to him—or at least he had heard—that this was a very aggressive disease, that he would require aggressive, multi-agent chemotherapy, but despite the therapy, they did not really believe his chances of long-term survival were very good. He came into my office with his mother and father—lovely people, all of them—and I basically agreed that he did have T-immunoblastic sarcoma, that he would require multi-agent chemotherapy, but here the story changed a little. I told him that this treatment had been able to cure some people—that was true. I told him that I didn't know whether or not he would be the one to be cured. but that even if the chance for that was only 1%, if he was the 1%, then the fact remained that the chance would be 100% for him. Since I really had no way of predicting whether or not he would make it, and since there was no question at all that long-term survival was a possibility, then why didn't we just assume that he was going to do well, and why didn't we just go for it, with a positive attitude and a good fight.

Well, we did go for it, and he went into remission, which lasted about a year. It was a good year. I knew it, and he knew it, and his folks knew it. At the end of the year, he relapsed, and he died several months later. Years have passed, and whenever I call his mother, consistently, every time, she has always begun our conversation by thanking me profusely for having allowed Paul to live that year instead of dying that year. It's a real subtlety, but it means everything.